Prof. Hanan Hamamy - Medical genetics education and research, focusing on community genetics, genetic counseling, genetic education and consanguinity

Training course in basic genetic counseling and community genetic services for primary health care personnel and family physicians. Adopted from the courses given at the National Centre for Diabetes Endocrinology and Genetics in collaboration with the Ministry of Health and WHO Amman, Jordan

Two weeks full-time course (10-200 participants: physicians and nurses)

Prepared and implemented by: Dr Hanan Hamamy, Professor Human Genetics

Objectives

Training and education of primary health care workers and family practitioners on public health approaches for the community prevention and control of genetic and congenital disorders and on the basic principles and application of genetic counseling at the primary health care level.

Prevention of congenital and genetic disorders at the population level depends on a combination of basic public health measures and the education and involvement of the primary health care network.

Genetic approaches appropriate at the primary health care level include:

- 1. Preconception counseling information
- 2. Screening and pre-screening counseling for premarital carrier detection programs and neonatal screening
- 3. Post-screening counseling for couples not at risk and referral of at risk couples
- 4. Identification and referral of individuals and families at increased genetic risk to specialized centers
- 5. Counseling related to consanguinity and referral when indicated

Role of primary health care personnel and family physicians in basic community genetics

The following training and education is needed:

- 1. Training in taking and recording a basic genetic family history, including pedigree construction for large consanguineous families
- 2. Guidelines on detecting possible genetic risks and where and when to refer
- 3. Training in the basic ethical principles and techniques of genetic counseling
- 4. Training in preconception counseling
- 5. Training in prescreening counseling, how to detect at risk couples or individuals and appropriate referral
- 6. Information on the advantages and disadvantages of consanguineous marriages
- 7. Information on common genetic disorders in the community

- 8. Access to appropriate information materials for patients, families and the general public
- 9. Information on the existing specialist services and patient and family support organizations
- 10. Information on genetic programs that would be introduced on the national level

Curriculum

This is a full-time two weeks course aiming to train and educate family and primary health care physicians and nurses in basic principles of first level genetic counseling. This includes pre-conception, pre-screening, and premarital counseling and the timely referral of at risk couples to specialized centers

Theoretical hours include seminars, formal presentations and discussions 35 hours Practical hours 15 hours

Quiz + final exam (2 hours)

Basic theoretical courses

- 1. Principles of Human Genetics (10 hours)
- 2. Principles of Genetic Counseling (9 hours)
- 3. Common disorders in Jordan and special topics in clinical genetics (9 hours)
- 4. Special topics and discussions (7 hours)

Principles of Human Genetics (10 hours)

- 1. Introduction: cell cycle, mitosis, meiosis, DNA structure and function, chromosomes and cytogenetic techniques. (2hours)
- 2. Basic molecular genetics and techniques (2 hours)
- 3. Single gene disorders and pedigree construction (3 hours)
- 4. Chromosome disorders (2 hours)
- 5. Other modes of inheritance (1 hour)

Principles of Genetic Counseling (9 hours)

- 1. Basic principles, aims, and ethical issues in genetic counseling (2 hour)
- 2. Preconception counseling (1 hour)
- 3. Consanguinity and counseling (1 hour)
- 4. Premarital screening programs and counseling(1 hour)
- 5. Newborn screening and counseling (1 hour)
- 6. counseling for chronic non-communicable diseases (1 hour)
- 7. Community education (1 hour)
- 8. Referral and information on specialized genetic services in Jordan (1 hour)

Approach to Common genetic disorders in Jordan and special syndromes

- 1. Epidemiology of hereditary disease and congenital malformations in Jordan (1hour)
- 2. Thalassemia, sickle cell anemia and G6PD deficiency (2 hours)
- 3. Phenylketonuria and primary hypothyroidism (1 hour)
- 4. Familial Mediterranean fever (1 hour)
- 5. Congenital adrenal hyperplasia and ambiguous genitalia at birth(1 hour)
- 6. Deafness and speech disorders (1 hour)
- 7. Mental retardation (1 hour)
- 8. Down syndrome (1 hour)

Special topics and discussions

- 1. Congenital malformations and teratology (1 hour)
- 2. Normal and abnormal growth of infants and children (1hour)
- 3. Dysmorphology (1 hour)
- 4. Recognition of uncommon and rare syndromes (1 hour)
- 5. Prenatal screening and diagnosis (1hour)
- 6. Discussions (2 hours)

Practical Sessions

Practical lab rotations

Problem based learning in genetic counseling

Supervised genetic counseling sessions / 2 students

Seminars prepared by participants on common disorders in the community and special topics

Visits to special schools (mental retardation, deafness)

Practical sessions on accessing genetic databases